



Privacy Notice

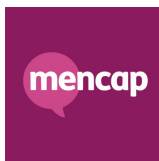
OPTICAL: Optimising Paediatric Transition to Intensive Care for Adults



What is the OPTICAL study?

We want to improve the care for young people as they move from child to adult intensive care. The study Chief Investigator is Professor Sonya Crowe and the Principal Investigator is Dr Padmanabhan Ramnarayan.

To understand how to improve your experiences, we will be working with people from Great Ormond Street Hospital (GOSH) and the charities MenCap, WellChild and, ICUSteps to hear from young people and their families.



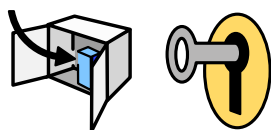
Your Data:

As part of our study we will use information about you from national sources such as health and hospital information. We will also like to hear from you about your experiences in hospitals in interviews, surveys and online forums if you would like to share them.



Your Privacy:

All of the data used by the OPTICAL study will have any information that might let people know who you are taken out and replaced by a study ID number. This means that all of your information will be kept private and UCL will **not** know your name, date of birth, or address.



Looking After Your Data:

Your health data and any survey answers will be kept on secure, password protected servers at UCL and GOSH.

How to Contact Us About Using Your Data



If you would like your information to be removed from the study at **any time** you can contact one of the following:

If you would like your data collected from national data sources to be removed from our study please contact:

PICANet: a.c.temple@leeds.ac.uk

ICNARC: DPO@icnarc.org

UCL: Data-protection@ucl.ac.uk

If you would like your answers from interviews to be removed please contact:

jo.wray@gosh.nhs.uk

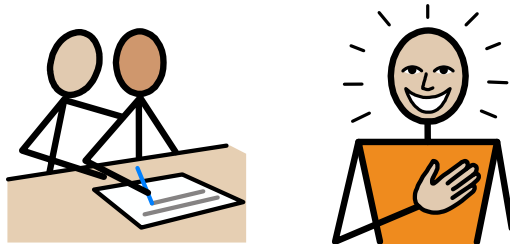
your.data@gosh.nhs.uk.

If you would like your answers from online forums to be removed please contact the charity whose forum you joined:

MenCap: DPO@mencap.org.uk

ICUSteps: contact@icusteps.org

WellChild: info@wellchild.org.uk



And if you have any questions or concerns about your data or need any help during the study please contact the study Chief Investigator Professor Sonya Crowe at: sonya.crowe@ucl.ac.uk